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## Amplify Your Narrative: Exploring the Power of Storytelling with African American and Indigenous Communities in Pediatric Cancer Treatment

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**Amplify Your Narrative: Exploring the Power of Storytelling with African American and  
Indigenous Communities in Pediatric Cancer Treatment**

Capstone Thesis

Lesley University

April 30, 2024

Trinity Perry

Clinical Mental Health Counseling with Drama Therapy

Dr. Laura Wood, PhD, RDT/BCT

### **Abstract**

This literature review investigated the empowering nature of storytelling with Black and Indigenous communities undergoing pediatric cancer treatment. It explored the roles of systemic racism, anti-Black racism, culture, spirituality, and intersectionality in shaping narratives about westernized healthcare. Furthermore, the review examined the concepts of anti-black racism, systemic racism, racial disparities in westernized healthcare, marginalized children's experience in pediatric cancer treatment, storytelling in African American and Indigenous communities, and storytelling through the lens of drama therapy. Evidence is presented that underlines the psychological impact of the previously mentioned components, and how community engagement and storytelling provide a means of attunement, hope, advocacy, and connection. Storytelling is explored from the lens of cultural sensitivity, and the acknowledged as a fundamental component of Black and Indigenous culture, not merely an optional tool. The drama therapy core processes are considered in relationship to storytelling as a means of suggesting future embodied, culturally, and spiritually inclusive practices.

*Keywords:* embodied storytelling, drama therapy, African American, Black, Indigenous Communities, BIPOC, storytelling, anti-Black racism, systemic racism, intersectionality

# **Amplify Your Narrative: Exploring the Power of Storytelling with African American and Indigenous Communities in Pediatric Cancer Treatment**

## **Introduction**

Settler colonialism, cultural genocide, white supremacy, and systemic racism are ideals and mechanisms that continue to attempt to justify the oppression, exclusion, and silencing of minority groups, such as Black and Indigenous peoples (Liu et al., 2023; McNeil-Young et al., 2023). “White Supremacy is the ideological belief system that promotes the superiority of White people and justifies the subordination, dehumanization, and oppression of Black people and other Black, indigenous, and people of color” (McNeil-Young et al., 2023, p. 276). For this thesis exploration, “Black” and “Indigenous” will be used in a capitalized form due to their reference to a group of people notoriously silenced, to provide a sense of empowerment, and “white” will be lowercased as it is an “unstable social construct” used to maintain systems of power and oppression (Liu et al., 2023, p. 245). For this paper, African American and Black will be used interchangeably, and Indigenous people and communities will be used as a broad term to represent but that cannot ethically encompass and represent all First Nation peoples. From the creation of reservoirs, land theft, police brutality, extreme violence, mass incarceration, victimization, and economic, racial, and health disparities, minority populations experience and are witness to extreme acts of individual, institutional, systemic, cultural, and environmental racism every day (Liu et al., 2023; McNeil-Young et al., 2023). Anti-Black racism, “is defined as the system of beliefs and practices that attack, erode, and limit the humanity of Black people” (McNeil-Young et al., 2023, p. 276).

While research exists on Indigenous communities (Brandenburger et al., 2017; Browne et al., 2016; Napoli, 2019; Terpstra et al., 2021), very little exists with interventions cocreated for

the benefit of the population served (Caxaj, 2015). Additionally, there is minimal research looking at the merging of drama therapy and Indigenous communities, and the broader scope of expressive therapies (Lee Soon, 2016). Lastly, there is a highlight in the literature of an acknowledgment that interventions for Indigenous communities are rooted in Westernized standards of care with no action steps to remedy this practice that is not culturally sensitive or inclusive (Garvey et al., 2020; Gifford et al., 2021). This review will highlight the gaps in research and potential areas for expansion. This literature review will cover the disparities in holistic health experienced by Black and Indigenous communities receiving pediatric cancer treatment, an overview of the drama therapy core processes, storytelling, and how these components can be combined to create interventions for minority populations in the future. The purpose of this literature review is to survey the literature to examine if a connection exists between storytelling with Indigenous and Black communities in pediatric cancer treatment, and how systemic racism, anti-Black racism, and intersectionality play a role in holistic well-being and survivorship.

### **Bracketing Personal Identity**

With the focus of this thesis on storytelling in Black and Indigenous communities, it is worth noting that this writer identifies as a Black, Indigenous, cisgender woman of color raised within Westernized culture and all the discrimination, oppression, and biases that those intersecting identities may entail. This writer was born and raised in Louisiana on the land of the Chahta Yakni (Choctaw) with familiar ties to the Avoyel tribe and is writing this thesis from Massachusetts on the land of the Naumkeag. This writer acknowledges that the perspectives of Indigenous communities are shared from Westernized, academic, peer-reviewed articles, that are accessible at this time, and ethically cannot speak for the encompassing experiences of every

Indigenous community. As an individual who identifies as BIPOC, has first-hand experiences of systemic racism, anti-Black racism, white supremacy, and has felt holistically unwell as a medically compromised child, the process of amplifying one's narrative holds a potent influence that should be named before going into this literature review. This writer holds strong connections to the Black community in her personal and professional life and has personal experiences, opinions, and preconceived notions on the Black experience that fuels the flame of this literature review. This writer acknowledges the limitations present because personal biases cannot be removed fully and hopes that this level of transparency minimizes unavoidable biases.

### **Literature Review**

The goal of this literature review is to gather peer-reviewed literature that may be used in the future to create storytelling interventions with African American and Indigenous communities. Within our Westernized healthcare system, one may assume that individuals are evaluated and treated equally when they need healthcare treatment. However, studies have shown that there are racial disparities within the medical model that point to minorities being treated with a lower level of empathy, compassion, or in-depth care due to implicit racial bias (Beltrami et al., 2022). "Implicit racial biases are associations about people based on race made unconsciously by individuals that can cause them to act discriminatorily. One study showed that pediatric oncologists believe that racial/ethnic minority parents want less information than other parents, leading them to provide incomplete information about their child's prognosis" (Beltrami et al., 2022, p. 6). Implicit racial bias can lead to less information being provided to minority families, which then aids in an increase in medical mistrust, lower satisfaction with treatment, leaving against medical advice, and a lower level of communication between families and clinicians (Pederson et al., 2022). However, implicit racial bias is one component of a broader

framework that specifically focuses on unconscious biases at the individual level but does not account for the system at large (Feagin & Bennefield, 2014). Geneviève et al. (2023) noted that the gap in our healthcare system is an issue of systematic, anti-Black, institutional, and interpersonal racism. Additionally, these forms of racism become internalized which leads to higher levels of medical mistrust in minority populations (Geneviève et al., 2023). Internalized racism is a direct result of white supremacy, systemic racism (including anti-indigeneity), institutional racism, structural racism, and Black racism (Anderson, 2013). The current exploration will focus primarily on systematic and anti-Black racism.

### **Understanding Systemic Racism and Anti-Black Racism**

When an individual thinks about racism, the personal acts of bigotry, slurs, disrespect, stigmatization, and exclusion come to mind. Racism is a socially constructed disease that permeates every facet of modern-day society (Liu et al., 2023). Racism names white people as the superior race, and all non-white individuals as the subordinate minorities (Liu et al., 2023; McNeil-Young et al., 2023). Anderson (2013) stated, “Racism is the systematic disadvantage of certain groups, as well as the systematic privilege of the dominant group” (p. 57). Systemic racism is often subtle, invisible, and difficult to spot in the individuals who benefit from the system, white people. Systemic racism is often used interchangeably with structural and institutional racism. However, there are key differences between these terms. Systemic racism is a form of racism embedded into every system, such as politics, health care, legal, and school systems (Anderson, 2013). Structural racism focuses on the practices in place like unjust laws, policies, and norms. Banaji et al. (2021) stated, “Systemic racism is said to occur when racially unequal opportunities and outcomes are inbuilt or intrinsic to the operation of a society’s structures... permeates a society’s (a) institutional structures (practices, policies, climate), (b)

social structures (state/federal programs, laws, culture), (c) individual mental structures (e.g., learning, memory, attitudes, beliefs, values), and (d) everyday interaction patterns (norms, scripts, habits)” (p. 2). The theory of systemic racism is grounded in critical race theory which is a theory that believes racism is normalized, purposeful, and not unpremeditated (Liu et al., 2023). The result of systemic racism is the continued oppression of non-white individuals, a toll on the mind, body, and soul, and the development of survival skills to combat the racism experienced everyday (Lewis, 2023; McNeil-Young et al., 2023).

Anti-Black Racism is, “systemic and institutional racial discrimination that has historically subjugated, marginalized and dehumanized people of African descent... [it]asserts the inferiority of Black people through oppressive stereotypes, bias, prejudices, and other forms of discriminatory actions” (Duhaney et al., 2022, p. 285). The concept of Anti-Blackness is rooted in slavery, colonialism, white supremacy, and silencing Black narratives. Anti-Black racism aims to not only silence Black people but has the goal to eradicate non-white people, based on skin color alone. Anti-Black racism is an overlap of individual, systemic, and cultural racism that specifically targets black people (McNeil-Young et al., 2023). The constant oppression and discrimination experienced by Black people leads to racial trauma. Racial trauma negatively impacts the holistic health of the black community and furthers mistrust in health professionals, and racial disparities (Duhaney et al., 2022; McNeil-Young et al., 2023). Liu et al. (2023) denoted that anti-Black racism is multilayered and hinders the right of Black people to take up time or space. Furthermore, within our white-dominated society, Black people are seen as socially “dead”, inhumane, and undeserving of occupying a physical space (Duhaney et al., 2022; Liu et al., 2023; McNeil-Young et al., 2023). Finally, Liu et al. (2023) stated that because



racist beliefs and behaviors are implanted in and uplifted by the system, most Black people will never have to experience straightforward forms of racism to feel the effects of systemic racism.

### ***Historical Context***

To understand the permanence of modern-day racism, a snapshot of history is ideal to contextualize this thesis.

#### **First Nation Peoples**

The start of the recognition of race and property dates to early colonialism, and the eradication and displacement of Indigenous peoples. Liu et al. (2023) “cannot stress enough the multilayers of oppression and racial violence that were and continue to be inflicted upon Indigenous peoples in the U.S. That we even speak of “property,” at all, in relation to white space must be anchored in settler colonialism (i.e., land theft, displacement of Indigenous peoples)” (p. 245). The systems in place reflect a Black-White paradigm, where all minorities are compared to Black folks as the preferred minority during discussions of race, ethnicity, and social justice in America, including Indigenous communities (Banaji et al., 2021; Geneviève et al., 2023). Fraser et al. (2021), located in Quebec, pointed out the emphasis on interpersonal racism, the lack of acknowledgment of systemic racism within their society, and the impact on Indigenous communities by defining systemic racism as, “the sum of disproportionate exclusionary effects resulting from the combined effect of prejudice and stereotypical attitudes, often unconscious, and policies and practices generally adopted without taking into account the characteristics of members of groups covered by the prohibition of discrimination” (p. 1). There has been an attempt to erase Indigenous communities from history. Byrne (2017) provided a powerful metaphor for how Indigenous people should be viewed in our world by stating, “Indigenous people are “caretakers of the earth” who live in harmony with nature and, as

Alexander Ewen (1994) noted, “live under original laws, are an endangered species and may soon, like the rain forests disappear. Along with the assault on our peoples, our governments are colonized, our lands occupied and stolen, our religious freedoms denied, and our treaties broken” (p. 6). Indigenous communities were and still are being hunted and should be protected as if they were a community of beings threatened by extinction.

### **African American**

In addition to the displacement of Indigenous peoples, African Americans, or Black people, were enslaved, seen as unequal, and used for free labor. The Jim Crow laws were put into place in the late 19th century and placed white people as superior to black people in every facet of society (Banaji, 2021). Segregation was supported, intentionally normalized, enforced, and made lawful. Black people were intensely populated in the southern region of the United States and seen inside poor rural areas, bottom-barrel jobs, and separated from society before the start of the Great (Black) Migration (Collins & Wanamaker, 2015). The Great (Black) Migration marks the period when African Americans began to move from the rural southern region of the United States to bigger cities in search of better jobs (Banaji, 2021). This time also marks the start of segregated neighborhoods, and the creation of the “ghetto” (Banaji, 2021). Racism became capitalized or monetized for the benefit of white people through the exploitation, and displacement of Black and Indigenous communities (Liu et al., 2023). In looking at the effects of European colonialism on Indigenous and Black communities, Liu et al. (2023) stated, “capitalism evolved from European feudalism, the accounting of Black people who were enslaved...anti-Blackness flourished during European colonial conquests on the African continent, and anti-Blackness synthesized with anti-indigenous beliefs and practices (i.e., land

theft, genocide, and indoctrination) in the Americas so that white settler colonials could cultivate riches for their imperial investors” (p. 248).

Furthermore, the experimentation and exploitation of Black bodies for the advancement of medical knowledge and practice is how the field of public health and medicine originated in the 19th century (Banaji, 2021). Enslaved black women were given to white physicians to be used as lab rats, and often these experimental treatments would not be attempted on white women (Feagin & Bennefield, 2014). In the 20th century, an unfathomable number of Black lives were taken due to medical experimentation, sterilization, hysterectomies, maladaptive eugenics, testing of birth control, withholding of treatment for syphilis, and the denial of curative practices for cancer treatment (Feagin & Bennefield, 2014). More specifically, the Tuskegee Experiment between 1932 and 1972, was a time when the US Public Health Service conducted unethical experiments on Black men with noncontagious syphilis (Jones & Reverby, 2022). However, the doctors were not truthful with the participants and told them they were being treated for an unspecified illness because they had “bad blood” (Jones & Reverby, 2022). Additionally, researchers did not obtain informed consent, or offer the treatment after it was made available, which is a major violation of conducting ethical research (Lombardo & Dorr, 2006). As a result, participants underwent painful procedures, like spinal taps, passed syphilis onto their partners, and developed further painful health complications. While the Tuskegee experiment changed the laws of human subject research to ensure beneficence, respect, safety, justice, and ethical practice, it furthered the medical mistrust of African Americans and their willingness to participate in research studies (Shavers et al., 2000). While Black people, especially Black women, are no longer experimented on in the same fashion, “Inhumane experimentation transformed into lack of access to health insurance and health care and into

provider bias” (Ray, 2022, p. S46). Due to these early practices of discrimination, stigmatization, exclusion, and simply not being invited to participate in research studies, there continue to be racial disparities within the Westernized healthcare system.

When looking back to the period of slavery and the ongoing unethical trauma to Black and Indigenous bodies, oral storytelling was heavily relied on to provide a sense of autonomy (McNeil-Young et al., 2023). Black slaves relied heavily on oral traditions, storytelling, dance, and music to maintain a sense of hope, resilience, and connection (Beach et al., 2020; McNeil-Young et al., 2023). Slave owners constantly lived in a state of fear of rebellion and would not allow slaves to be able to read or write. So, information was shared through oral storytelling, songs, and dance. The origins of race, separation of identity, creation of racism, anti-Black racism, and eradication of Indigenous communities are components of a system that is multidimensional, and complex and deserves a more in-depth exploration than what will be featured in this literature review.

### **[Racial] Disparities in Westernized Healthcare**

Despite the changes to research regulations to protect human subjects born out of the harm to Black bodies, racial disparities persist and seeps out in other ways. Disparities exist related to race/ethnicity, socioeconomic status, education, accessibility to health insurance, and invitation to interventions are barriers to receiving medical treatment, specifically cancer treatment. Previous research has focused mainly on an investigation of a segment of oppression, like socioeconomic class, gender, or race while not looking at the overlap or relationship of these factors (de Mesa et al., 2023). The intersection of an individual's social positionality must be considered when contemplating disparities in healthcare. Examining intersectionality in the face of oppression is looking at how the merging of identities shapes lived experiences to the power

structures held in society (Wilson et al., 2019). Kimberlé Crenshaw (2013), a feminist, originally coined the term to describe the struggles of Black and Indigenous feminists during the rise of critical race studies and Black feminism. Intersectionality considers factors such as race, class, gender, disability, and sexuality that shape an individual within broader structures and power systems.

The intersection of systems of oppression and discrimination is key to understanding the experiences of Black and Indigenous communities and cancer treatment outcomes. The intersection of being Black or Indigenous, female, and lower-class within a system of oppression makes it more likely that an individual will experience varying forms of racism (Lewis, 2023). Black and brown folks are not offered to feel because of the stereotypes associated with the community, such as being the angry Black woman, the threatening Black man, or the illiterate Native American Indian (Beach et al., 2020; Thrash, 2022). The label is given as a symbol of containment, or to compartmentalize identity. Thrash (2022) stated, “If society shows you that your life is not worth as much as your white counterpart, after a while, you start to believe it” (p.111). Labeling and stereotyping can have psychological and physiological effects on minority groups (Lewis, 2023; Thrash, 2022).

### **Westernized Cancer Treatment**

The use of stereotypes to justify the oppression, discrimination, and healthcare disparities experienced by Black and Indigenous communities becomes more apparent when surveying the available literature on cancer treatment outcomes (Lewis, 2023). Cancer remains one of the leading causes of death for Black and Indigenous communities, especially in childhood cancers (Beach et al., 2020; Penner et al., 2012). Feagin (2014) reported, “black women are less likely than whites to be prescribed innovative cancer treatments or combination therapy or to be

included in important research on these cancers” (p.10) despite high rates of cancer within this community. African American women are more likely to die from breast cancer, black individuals are less likely to be offered standard treatment options for lung cancer, black and indigenous communities are less likely to receive organ transplants than white individuals, and black communities are more likely to have amputations, hysterectomies, or testicles removed without the offering of alternative treatment options (Feagin, 2014; Kehm et al., 2018; Penner et al., 2012).

As previously mentioned, Indigenous communities have suffered from colonization, cultural genocide, and generational trauma (Napoli, 2019). The barriers faced by Indigenous communities have been previously summed up as a result of colonization, social exclusion, and systemic racism that has led to poverty, unsafe cultural practices, and distrust in Westernized healthcare procedures (Gifford et al., 2021). Health and wellness in Indigenous communities is a spiritual practice and journey that is not an isolated experience, but one done in the community. When spirituality is not addressed in cancer treatment, Indigenous communities are being stripped of their cultural ways, state of being, and forced to endure social and spiritual stress. “These cumulative losses in addition to systemic racism, are linked to poor physical, emotional, mental, and spiritual health, contribute to the tremendous serious illness burden experienced by AIs [American Indians], and greatly influence the lack of trust in Westernized medicine” (Isaacson et al., 2022, p. 269). Spirituality is wellness, or the center point and core of a Native individual's existence (Hodge et al., 2009; Isaacson et al., 2022). Hodge et al. (2009) stated, “We are not so much humans on a spiritual journey as spirits on a human journey—a journey in which our spirits will continue to exist in the hereafter” (p. 213-214). All living things are connected, and this interconnectedness is crucial to wellness, or a major area of emphasis during times of

illness or cancer treatment (Gifford et al., 2021; Hodge et al., 2009; Terpstra et al., 2021). In addition, the lack of culturally inclusive spiritual practices, access to healthcare services, distance to cancer centers, lengthy commutes, and willingness to conform to Westernized practices are components to consider when examining disparities in cancer treatment for Indigenous communities. Garvey et al. (2020) acknowledged that a major component of stress for Indigenous communities in cancer treatment may be the disrespect or lack of acknowledgment of their culture and belief system. Historically, Indigenous communities were pushed to reservoirs, removed from urban areas, and pushed to rural outskirts, which added an accessibility barrier to receiving cancer treatment (Garvey et al., 2020; Hodge et al., 2009). Previous research has named experiences of inequality due to medical mistrust, non-adherence to treatment, accessibility, education, underrepresentation in clinical trials, language barriers, and prolonged exposure to systemic racism (Beltrami et al., 2022; de Mesa et al., 2023; Moore et al., 2022).

### **Marginalized Children and Cancer Treatment**

The intersection of race and systems of oppression becomes more complex when you consider the vulnerability of childhood (Beltrami et al., 2022), especially during pediatric cancer treatment when the vehicle of the body is fighting against cancer. Moore et al. (2022) stated that “In children from poorer households, social factors including access to health insurance and health care may play a particularly important role in determining disparities by race/ethnicity given their consequences on diagnosis delay or treatment interruption” (p. 12). Diagnosis delay is one main factor contributing to the mortality rate of children diagnosed with cancer (Beltrami et al., 2022). Diagnosis delay has been linked to socioeconomic differences, and lower-class individuals may not have access to health insurance, which then results in children not having access to treatment (Beltrami et al., 2022; de Mesa et al., 2023; Rosa et al., 2023). Additionally,

lower-class individuals make up the working class, and parents cannot get away from work, find additional childcare, or resources needed to take their children to be evaluated, or treated (de Mesa et al., 2023). Rosa et al. (2023) noted unjust care for Black and Indigenous families may include discrimination and biases from care clinicians, poor symptom management, and no effort to integrate the patients' spiritual and cultural values into treatment. Gifford et al. (2021) scoped the literature to find interventions that aided in cancer survivorship of Indigenous communities and found no significance in the community relevance of the interventions utilized. One finding was that over 50% of the interventions surveyed were focused on a physical component of holistic wellness such as access to healthcare, while only 4% of interventions focused on a spiritual aspect of wellness, which conforms to a Westernized healthcare module (Gifford et al., 2021). While relevance was rated lowly, the interventions were deemed culturally sensitive and appropriate. For children to receive adequate care and treatment, their caregivers must feel fully supported by the system and treatment providers. Families that are of lower socioeconomic status may not be able to afford innovative and expensive treatment options, as those may not be covered by insurance (Beltrami et al., 2022; Moore et al., 2022). Beltrami et al. (2022) searched peer-reviewed literature on healthcare disparities in childhood and offered that improving communication and decreasing language barriers, increasing health literacy and psychoeducation on diagnosis, and an increase in representation of minorities in clinical trials as possible interventions to decrease disparities and increase survivorship in pediatric cancer. Moore et al. (2022) reported that there is a higher risk of death for Black, Indigenous, and minority children with acute lymphoblastic leukemia, brain tumors, sarcomas, acute myeloid leukemia, neuroblastoma, and lymphomas. Additionally, researchers found that overall Black children have



lower survival rates than white children due to higher occurrences of nonadherence to preventative care and maintenance treatment (Moore et al., 2022).

### **Indigenous Storytelling**

To combat racist narratives, stereotypes, oppression, and discrimination in western healthcare storytelling can be incorporated to aid in holistic wellness. Stories are a living being. They are a gift (Garrouette & Westcott, 2013; Hodge et al., 2009). Storytelling in Indigenous communities is not a “tool” to be used because it is embedded into the culture, and a way of life. To eliminate this core component of Indigenous culture is not truly to meet the individual where they are (Caxaj, 2015). It is stripping them down and forcing them to conform to Westernized medical practices (Byrne, 2017). Stories are used to inform life and provide a way to make meaning (Caxaj, 2015; Garrouette & Westcott, 2013). Indigenous communities view storytelling as “a living being. It’s alive. So it’s important to follow the principle of reciprocity: by giving a gift and asking the story to impart itself to us in a way that will help us gain insight and knowledge, and perhaps even wisdom” (Garrouette & Westcott, 2013, p.63). Stories allow for a bridge of connection to be formed and empower an individual to become relational, which speaks to the nature of community within Indigenous culture.

### ***Talking Circles***

Storytelling in Indigenous communities can include different components, or processes that are beneficial. Talking circles, a practice within Indigenous communities, have been appropriated to fit the realm of group therapy by imitating the form of a circle to promote communication, increase the likelihood that all group members have a voice, and promote a sense of safety to share vulnerable narratives in the therapeutic environment (Brandenburger et al., 2017; Isaacson et al., 2022). Talking circles within Indigenous communities were created for

parliamentary purposes and then used to gather, teach, learn, and share in the community (Caxaj, 2015; Gifford et al., 2021; Wolf and Rickard, 2003). Wolf and Rickard (2003) stated the importance of the circle is that it is, “seen as sacred, representing the interconnectedness of all things (people, earth, moon, sun). Individuals were given the opportunity to express their thoughts on an issue in both large and small groups by continuing to go around the circle, recognizing the value of each speaker... instilled respect for another's viewpoint and encouraged members to be open to other viewpoints by listening with their heart while another individual speaks” (p. 39). Within the talking circle, some tribal communities may utilize a talking token, such as a talking stick, feather, or shell (Isaacson et al., 2023; Rieger et al., 2023). The use of the talking stick within the talking circles gives space for grounding, listening, trust-building, and dismantling positions of power (Isaacson et al., 2022). Within the field of play therapy and marriage and family therapy, the talking stick has been appropriated to improve communication and minimize interruptions with couples, and families (Hickey, 2003). The spiritual practice of the talking stick being a beacon to tribal ancestors has been lost in appropriating the talking stick as random household objects for couples and families (Hickey, 2003).

### ***Prayer***

Prayer, in the community or within talking circles, can be a form of storytelling for Indigenous communities. Prayer, whether in the traditional spiritual sense or a hybrid form with the influence of colonialism and Christianity, has been noted as a central practice of spirituality, and is nourishing when it is done alone or in the community (Isaacson et al., 2022). Indigenous tribes have sacred prayers known, respected, and recited by the community during times of celebration, healing, or to pay respect (Isaacson et al., 2022). Isaacson et al. (2022) noted from their research with Indigenous communities in the Great Plains region that prayer “brought

relatives from the Spirit World to come watch over her...provided a sense of security and healing for her, allowing her to realize she would survive cancer” (p.16). Prayer is central to and a foundational component of spirituality in Indigenous culture (Hodge et al., 2009). Prayer soothes the spirit, which then aids in restoring balance and well-being for Indigenous communities undergoing pediatric cancer treatment (Hodge et al., 2009; Isaacson et al., 2022). Garrouette & Westcott (2013) stated, “illness stories become important because they allow people to confront the fundamental separateness, and thus unknowability, of other subjectivities. They are vehicles by which isolated subjects invite others to imagine themselves into their experience...recognition that even though the other body is outside of mine, ‘over against me,’ this other has to do with me, as I with it” (p. 69). Within mainstream cancer treatment, Indigenous values and practices are not reflected, and this results in Indigenous people not seeking treatment. Garvey et al. (2020) took a scope of the literature and found that while there has been a rapid increase in general tools that are beneficial to the success of cancer treatment, very little attention has been given to the specific cultural and social context that can aid in better treatment outcomes for Indigenous communities receiving cancer treatment.

### **Black Storytelling**

Within the black community, “storytelling is one of the most valuable traditions within African diasporic cultures...stories are used to safeguard history, bolster collectivism, and share the matter-of-fact information needed for day-to-day survival...Black individual's utilize storytelling to resist racist mainstream narratives” (McNeil-Young et al., 2023, p. 277). Storytelling is used as a way for the black community to prepare for, cope with, and process anti-black racism, systemic racism, and racial trauma (Mosley, 2021; McNeil-Young et al., 2023). Through the power of storytelling, Black folks can heal from racial trauma while also nurturing

themselves and others in the community. Storytelling was previously used as a tool for survival when Blacks were enslaved and not allowed to read or write, and preserved as poems, chants, myths, stories, and narratives (Beach et al., 2020; Gates & Tatar, 2017). Beach et al. (2020) conducted a study looking at the theatrical production *When Cancer Calls...* which is a show based on real phone calls with white individuals dealing with their family member's cancer diagnosis, treatment, and death. The goal of the study was to determine if the cancer stories portrayed in the production would resonate with African American audience members' cancer experiences, despite the casting being only white individuals and families. Researchers found that Black and nonblack participants found the production to be cathartic, and authentic and that Black participants did not respond with any form of prejudice against whites. Black participants favored the production due to the nature of oral storytelling that was portrayed in the show. Beach et al. (2020) found that "Authentic oral storytelling about family health issues offers a powerful and empirically supported approach to health communication interventions and campaigns designed specifically to assist Black Americans with managing communication, illness, and disease" (p. 1527). Additionally, McNeil-Young et al. (2023) found that storytelling for the Black community recenters the black experience, resists westernized cultural dominance, takes control of the narratives associated with the Black community, impacts their life and those around them, increases their ability to effectively story through vulnerability, fuels activism and advocacy, and provides a sense of radical hope (Beach et al., 2020; Gates & Tatar, 2017; McNeil-Young et al., 2023). The Black community fosters relationships and connections, gains new perspectives, feels empowered, challenges the dominant narratives held in society, and promotes collective healing through stories (McNeil-Young et al., 2023; Williams et al., 2003).

### **Storytelling in Drama Therapy**

In the field of drama therapy, storytelling has been utilized as an intervention method across populations and settings to aid in addressing systemic and mental health barriers, and coping with stress (Beach et al., 2020; Lahad & Jennings, 1992; Versace, 2021). The six-piece story-making assessment tool emerged in 1992 by Lahad, after building off Gersie's (1993) foundational use of story, to gauge the therapeutic potential of clients engaging in the dramatic material (Lahad & Jennings 1992; Lahad, 2012). Since then, researchers have used the method across varying populations, but no non-Western researchers have used or adapted the method (Versaci, 2021). The method has been utilized in the fundamentals of Westernized storytelling. The notion that stories have a beginning, middle, and end, or that start with the well-known "Once Upon a Time" is a Westernized form of storytelling (King, 2003). The emphasis on the protagonist, conflict, climax, and resolution of a story are normalized, incorporated into early childhood education curriculum, and taught as the framework for "proper" storytelling (King, 2003). Conflict in stories is a Westernized concept that is not present as a necessity in Indigenous stories (King, 2003). Currently, there is a lack of literature on the six-piece story method being utilized or adapted for Indigenous communities, and the foundation of the storytelling method does not represent the spirit of storytelling within Indigenous communities.

Rebecca Versaci adapted the six-piece story method to utilize with siblings of infants in the NICU. Through her exploration, Versaci (2021) found that storytelling allowed children in pediatric settings to express emotion for themselves and their caregivers, explore the role they play within their family system, take on roles and positions of power, take control of their narrative, and project aspects of themselves and their emotions into their story characters. Versaci's (2021) study findings build upon Stephanie Omens (2014) work with medically compromised children and their families. Through Omens (2014) work she utilized DvT to

create a structure and container for traumatic experiences faced by medically compromised children and denoted that the playspace provides the opportunity to go beyond reality and play with the fear of the medical environment and treatment, express emotion, explore empowering roles, and imagine alternate realities (Omens, 2024).

### ***Role Method***

Robert Landy (1996) built on Moreno's introduction of role in psychotherapy and created the role taxonomy. Landy (1996) denoted that humans are made up of flexible and adaptable roles that interact with one another on the stage of life. Landy utilized Western plays to create the role taxonomy, and that is reflected within the roles presented in the original taxonomy (1996). In drama therapy, roles can be utilized as a guide for individuals to understand the intersecting identities that make up their personhood, while examining what roles are forced to be overused in a system of oppression and discrimination, and which roles are suppressed (Emunah, 2019). Landy's (1996) work was expanded by Adam Stevens (2023) in the creation of the Black American Role Taxonomy (BART), which yielded over 50 roles centered on the Black experience. While Stevens gave an in-depth exploration of four roles, BART allows Black folks the autonomy to reclaim, name, and portray empowering roles not including in the original taxonomy (Stevens, 2023). Role exploration and presentation depend on whether there is a container of safety that has been established, which is portrayed in Stevens (2023) work. With a lack of hostility, role exploration can aid in a secure mind, body, and soul connection. In pediatric cancer treatment, a child may put on the role of 'storyteller', but the power of the role and the story comes from not being confined to westernized components found in the six-piece story.

### **Drama Therapy Core Processes and Story**

The notion of balance is key to wellness within Indigenous communities, and the mind, body, and soul connection is central to spirituality (Hodge et al., 2009). Within the black community, religion and spirituality are seen as crucial to wellness. Mutter and Neves (2010) found that there is value and importance in including a client's spiritual or religious view within treatment to bring awareness to the ideas, rituals, practices, and beliefs that inform the client's views of the world. The drama therapy core processes can aid in centering wellness through storytelling in pediatric cancer treatment.

### ***Distancing***

In drama therapy, the connection and balance of the mind, body, and soul in harmony can be reflected in the idea of aesthetic distance, or the ability to emote and think simultaneously without becoming flooded with emotion (Frydman et al., 2022). Aesthetic distance creates a state of harmony because it is not a stationary state of being, but a place of fluctuation that you can bob and weave in and out of (Landy, 1997). The use of distance in drama therapy allows for the creation of a safe enough space for clients to work through their barriers, empowers them to make new choices within the playspace, gain new perspectives, and change their narrative.

### ***Embodiment***

Embodiment, in drama therapy, is the intentional use of the vehicle of the body to allow clients to gain knowledge through sensory and emotional processing. The use of the body is political, representational of experiences of marginalization, and the main stressor for children with cancer. Frydman et al. (2022) named the opportunity for individuals to, "explore the personal, social, ecological, and/or political forces that influence one's experience of the body, including how the body may be socialized, racialized, gendered or otherwise viewed in specific

contexts” (p. 8). Researchers also acknowledged the mind, body, and soul connection and being consciously aware of intersecting identities (Frydman et al., 2022).

Omens (2014), a Developmental Transformations (DvT) practitioner, operates from the instability theory and the use of the playspace to enact alternate realities in the here and now. Omens (2014) described her work with medically compromised children as the ability to engage children and their families in play on the topics of their illness, treatment, fear, mistrust, and death. Omens (2014) denoted that embodiment is subjective and related to an internal processing of grappling with what it means to be in a state of unwell. Furthermore, the sense of the physical body (objective body), and subjective body makes up a unique experience of embodiment that surpasses what is thought possible (Omens, 2014).

### ***Dramatic Reality***

The playspace, in drama therapy, allows for the creation of an alternate, imaginative space where individuals can navigate traumatic experiences in a safe enough container that can lead to therapeutic change or a new perspective of their hospital experience (Omens, 2014; Versaci, 2021). Engagement in the playspace, or the dramatic reality, allows individuals to engage with their internal and external narratives, and an inner-held belief, behavior, or perception is made palpable (Frydman et al., 2022). Once this inner-held perception is externalized, the playspace becomes a safe enough container for children in pediatric cancer treatment to feel, question, challenge, confront, express, and reregulate themselves concerning their current stressors.

### ***Dramatic Projection***

The process of externalizing ideas, feelings, or perceptions into the playspace through a story is known as projection in drama therapy (Frydman et al., 2022; Versaci, 2021). Clients can



explore the projected material through dramatic play. When working with medically compromised children, puppets, masks, and medical instruments are common dramatic materials used with this population (Omens, 2014, Versace, 2021). The story itself can be viewed as a projective technique to aid in engaging with traumatic material at a safe enough distance that supports the ideas of balance, grounding, and community that are central to Black and Indigenous communities.

### **Discussion**

Within our Westernized healthcare system, racial and health disparities exist for Indigenous and Black communities. While the scope of this literature review focused on systemic racism at large, the field of drama therapy still has a long way to go regarding racial biases and cultural inclusivity. Geneviève et al. (2023) acknowledged how researchers across fields operate under the illusion that their field is free from racist influences, and implicit racial and ethnic biases. The field of drama therapy is not free of these illusive practices but has begun to address racial and ethnic biases in a growing body of literature (Capitman, 2021; Haen et al., 2024; Sajnani & Johnson, 2024; Senior, 2021; Tam, 2019; Williams, 2016). Cultural humility, and the acknowledgment of spiritual and religious beliefs, is crucial to working with African American and indigenous communities (Geneviève et al., 2023). Establishing a therapeutic relationship and community connection is key to increasing survivorship for communities who have been silenced and marginalized (Liu et al., 2023; McNeil-Young et al., 2023). There is research on health disparities and marginalized individuals' experiences within the Western healthcare system, and literature on these communities' use of storytelling in their community as a form of connection, knowledge sharing, activism, and religious or spiritual expression, but

there is no personalized data on individual experiences of the power of storytelling within pediatric hospital settings for Black and Indigenous folks.

### **Storytelling as a Live Being (Indigenous)**

For Indigenous communities, a story is a live gift embedded in the culture, to pass knowledge, teach, and be in community with one another (Caxaj, 2015; Garrouette & Westcott, 2013; Isaacson et al., 2022). Additionally, scholarly research on Indigenous communities is rarely done by and in cocreation with First Nation people (Napoli, 2019). Why, is it that an abundance of resources, time, and energy will be given towards animals going extinct, but the same if not more resources, time, and energy are not given to the original protectors of this land?

Additionally, it was noted that a major limitation in research involving Indigenous communities lacks the sense of giving back to the community and does not allow Indigenous peoples to decide what is relevant and useful (Browne et al., 2016; Gifford et al., 2021).

Regarding the power of storytelling for Indigenous communities, stories are used as a means for knowledge sharing, community engagement, spiritual grounding, and continuing traditional practices. During cancer treatment, stories have been shown to provide a sense of understanding, hope, peace, and attuning to the Indigenous communities' spiritual practices (Garvey et al., 202; Terpstra et al., 2021).

### **Storytelling for the Black Community**

For the Black community, stories are used to preserve history, instill hope, for liberation, and to promote and empower community connection (Mosley, 2021; McNeil-Young et al., 2023). Cancer remains one of the leading causes of death in children. Racial disparities exist due to systemic, anti-Black racism, and anti-Indigeneity practices that are embedded into systems of power that are designed to benefit white individuals. Minorities are underrepresented in the

research literature and are not being invited to participate in clinical trials, which increases the instances of diagnosis delay, limited health knowledge and education, and further medical mistrust (Beltrami et al., 2022; de Mesa et al., 2023; Moore et al., 2022). The underhanded implication is that Black and Indigenous communities are passive in exploring their treatment options in comparison to white groups with no regard to the nature of the system working against them. To provide the best ethical practices for Indigenous and Black communities, centering the cultural and spiritual practices of these communities would be beneficial. Black and Indigenous communities have notoriously been silenced, taken advantage of, and assigned labels and narratives that have become ingrained and integrated into modern-day society. Indigenous and Black communities would benefit from taking hold of the narratives that have been put upon them, changing the narrative, and then amplifying the new narrative within pediatric cancer treatment using storytelling. These communities of people have been deemed as lesser than others, unintelligent, incapable of making decisions for themselves, and stripped of their cultural practices (Garvey et al., 2020; Gifford et al., 2021; Napoli, 2019).

Furthermore, there is a lack of research on how intersectionality plays a role in cancer treatment outcomes for minority children. The current literature focuses on the acknowledgment that intersections exist within the imbalance of power structures without accounting for social, emotional, and mental well-being outside of systemic racism and the awareness of white supremacy. Previous research has focused on the physical deficits' minority populations face, and points of access, and not the full holistic picture (Gifford et al., 2021). Drama therapy's core processes of engagement in the playspace or dramatic reality, projection, and embodiment appear within the storytelling process (Frydman et al., 2022; Versaci, 2021). These core processes interact with one another and can be utilized in pediatric cancer treatment through stories to

pinpoint and process fears, understand, and prepare for treatment and loss, and take hold of the narrative of the projections of their illness journey. Drama therapist should be aware of how intersecting identities may affect the storytelling process and be intentional about the forms of storytelling used with minority communities. Additionally, children undergoing pediatric cancer treatment may engage in a new form of expression and connection during an isolative cancer treatment experience. Storytelling, from a non-westernized lens, could be utilized within sterilized, bleak hospital settings to promote a sense of control, and empowerment, increase culturally inclusive practices, and address the silencing of minority experiences.

### **Embodied Storytelling**

The physical and spiritual body is used in African American and Indigenous communities to share stories. Utilizing the mind, body, and soul connection, the objective and the subjective body, the essence of the individual spirit, the sense of grounding, and the main stressor (body) to offer an individual the ability to fully tell their story and bring about therapeutic change. From this literature review, this researcher offers the perspective of embodied storytelling. Embodied storytelling involves the intentional use of story, the subjective and objective body, and the acknowledgment, awareness, and inclusion of the individual spiritual, religious, and cultural beliefs held by the client in a safe enough space to voice, explore, and amplify individual narratives. Embodied storytelling invites participants to use their bodies, cultural practices, rituals, and knowledge to dive deeper into their lived experiences. The process of externalizing inner-held narratives allows the participants to project aspects of themselves onto dramatic material, such as puppets, poems, masks, ritualistic songs or dances, art mediums, or stories. The component of embodied storytelling that offers the potential of feeling empowered and

therapeutic change is the participants' ability to engage with any medium that is true to and speaks to their cultural identity, and the cocreation of a unique storytelling experience.

Drama therapist should incorporate spiritual and cultural sensitivity, utilize an array of dramatic mediums that speak to the individual experiences and identity of their clients, and allow for storying to emerge naturally in non-westernized ways. Drama therapist can be intentional in viewing the cultural identity of their clients as the stage for which their stories will emerge, be portrayed, and performed. Drama therapist should approach storytelling with Black and Indigenous communities with empathy, serenity, and humility. Drama therapist should utilize the tools available (dramatic projection, role taxonomy, embodiment, dramatic reality) to provide a space for Black and Indigenous communities to explore racial identity, inner held narratives, and honor the BIPOC experience within clinical and hospital settings. Drama therapist should utilize storytelling to challenge their biases, assumptions, and stereotypes in relation to working with Black and Indigenous communities. Dialogue around race, systemic racism, and the lived experiences of BIPOC folks should not be shied away from by drama therapist but integrated into clinical practice to minimize internalizing racism and forming negative views of oneself. Embodied storytelling allows for the unspoken to be witnessed, heard, and honored in a way that words cannot convey. A light can be shed on the spiritual and cultural practices within African American and Indigenous communities.

### **Implications for Further Research**

“What if we were to imagine possibilities wherein the eradication of racism and the creation of psychological health were about the making and claiming of space, and thus, the making and claiming of time for and by Black, Indigenous, Latinx, Asian, and other non-Black people of Color—untouched by whiteness?” (Liu et al., 2023, p. 246) Future research may dive

deeper into the individual components of embodied storytelling and how it differs from DvT, embodiment, role theory, and dramatic play. Additionally, future researchers may approach embodied storytelling from the lens of role theory and observe how the clinician's unique role systems interact with their client's story through a qualitative exploration. Another point of exploration may be centered around the unique way of approaching children's relationship to storytelling that is more inclusive and understanding of their intersecting identities while grappling with what it means to be in a body that is not only attacking you but also helping you tell your story. With the acknowledgment of gaps within the Western healthcare system and the observance of a lack of action steps, future researchers may focus on creating an intervention tailored to uplift minority folks' voices without societal pressure or constraints, change, and then amplify their narratives through an arts-based study, and further developed into a quantitative exploration. Lastly, future researchers may develop a method utilizing participatory action research to ensure Black and Indigenous peoples feel empowered during the research process. Given the horrors of past research for Black and Indigenous folks, future researchers should invite participants into the process from beginning to end, and engage in thorough debriefing, and follow-ups after the interventions and research has concluded.

## **Conclusion**

Humans are live beings that deserve, want, and need to be their authentic selves, which includes remaining true to their cultural backgrounds and personal narratives. Stories have been used as a means of knowledge sharing, preserving history, survival, and resisting mainstream narratives for African American communities (Mosley, 2021; McNeil-Young et al., 202). Stories in Indigenous communities are viewed as sacred, live, communal, and an aspect of the culture that empowers one to share vulnerable narratives (Isaacson et al., 2023; Rieger et al., 2023).

Additionally, it bridges the spirit world and the living realm and provides a sense of being held, watched over, and protected by the ancestors. This thesis explored the gaps in research on the lived experiences of Black and Indigenous communities within the Westernized healthcare system. More specifically, the intersection between holistic health, storytelling, drama therapy core processes, and pediatric cancer treatment for Black and Indigenous communities.

Storytelling serves to unite communities to provide a sense of empowerment, fuels the imagination to view the experiences of others, challenges the dominant narratives, provides a sense of radical hope, and cope with racial trauma (Beach et al., 2020; Gates & Tatar, 2017; Isaacson et al., 2022; McNeil-Young et al., 2023). For African American and Indigenous communities who have experienced systemic racism, anti-Black racism, colonialism, genocide, displacement, and white supremacy, embodied storytelling can serve as a bridge to working through medical and psychological trauma.

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**THESIS APPROVAL FORM**

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In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

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**Laura L Wood, PhD, RDT/BCT, LMHC**

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